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IN THE
Supreme Court of the United States
OCTOBER TERM, 1992

LEONARD E. HELLER, Secretary,
KENTUCKY CABINET FOR HUMAN RESOURCES,
Petitioner,
v.
SAMUEL DOE, by His Mother and Next Friend,
MARY DOE, *et al.*,
Respondents.

On Writ of Certiorari to the United States Court of Appeals for the Sixth Circuit

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AMICUS CURIAE BRIEF OF FOCUS ON COMMUNITY UNDERSTANDING AND SERVICES, INC. (FOCUS); PEOPLE FIRST OF NEBRASKA; PEOPLE FIRST OF RUSTON, LOUISIANA; PEOPLE FIRST OF TENNESSEE; AND PEOPLE FIRST OF WASHINGTON IN SUPPORT OF RESPONDENTS

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STATEMENT OF INTEREST

The groups filing this brief are part of the growing national movement of people with disabilities organizing to speak with a collective voice on their own behalf on issues directly affecting their lives. Our membership is composed entirely of people who have been labeled as having "mental retardation" or a "developmental disability." As will be evident from the materials presented in this brief, many of our members have been subjected to

life in various institutions, and our members have strong feelings and opinions about how this has affected our lives.

Focus on Community Understanding and Services, Inc. (FOCUS), is an Ohio non-profit corporation established to be a self-advocacy group for people who are labeled as having "developmental disabilities." Its mission statement calls on FOCUS to empower people by:

> 1) Creating and sustaining a forum for an open exchange among people with disabilities and other interested persons;
>
> 2) decreasing dependency and increasing inter-dependency through enhancing productivity, and self-determination of citizens with disabilities;
>
> 3) promoting education in regard to issues facing people with disabilities and the continuing need for additional ongoing research and advocacy; and
>
> 4) promoting the development, maintenance, and provision of appropriate quality services.

To fulfill this mission, FOCUS conducts state wide training in advocacy skills of people labeled as having a disability, and prepares educational material for its membership and clients. It has also undertaken initiatives to improve the availability of employment activities for its clients.

Growing out of local chapters, some of which have existed since 1975, People First of Nebraska has been a statewide self-advocacy organization since 1985. Its members are all people who are labeled as "disabled." It conducts educational activities for its members; legislative advocacy on issues of concern; and sponsors and organizes an annual convention. People First of Nebraska has taken a formal position calling for the closure of the Beatrice (Nebraska) Developmental Center, a large state run institution for people labeled as having mental retardation.

People First of Ruston, Louisiana, was formed in 1983 by a group of people with mental and physical handicapping conditions who wanted their opinions heard concerning the types of services and treatment they were receiving. Its members include individuals who live independently, in large residential institutions, in community residential programs, and with their families. People First of Ruston provides training to its members on self-advocacy and their right to participate in the political process.

People First of Tennessee is a statewide advocacy organization in the state of Tennesse, where it exists as a non-profit corporation. It has over eight hundred members, all of whom are labeled as "disabled."

The purposes of People First of Tennessee are:

> 1) To promote the philosophy that everyone, no matter what disability he or she has or its severity, has the same basic civil rights and responsibilities;
>
> 2) to advocate and defend the rights of persons with disabilities in the areas of employment, education, housing, and transportation; and
>
> 3) to provide a way for persons with disabilities to express and remedy their concerns and enhance their well being.

In advancing these goals, People First of Tennessee has engaged in legislative and legal advocacy, *e.g.*, *People First of Tennessee, et al. v. The Arlington Developmental Center, et al.*, No. 3-91-1026 (M.D. Tenn., complaint filed December 12, 1991), as well as conducting training for members and other people labeled as having disabilities. In 1991, People First of Tennessee hosted a national conference of "self-advocacy" organizations, at which time a steering committee for a national group, Self Advocates Becoming Empowered, was established.

People First of Washington began as a local chapter in 1974. After statewide conventions in 1978 and 1979,

the statewide organization was created in 1980, with 17 local chapters. It now has 36 local chapters in Washington. Its members are all people who are labeled as having a disability. Its membership also includes people with severe or multiple disabilities. People First of Washington provides training to its members in self-advocacy and employment rights. It works to increase public awareness and understanding of people with disabilities, to increase its members' involvement in the political process, and to advocate for additional services and against budget cuts. People First of Washington also sponsors an annual statewide "People First" conference.

Amici file this brief with the consent of the parties. The statements of consent are on file with the Clerk.

SUMMARY OF ARGUMENT

1) People with mental retardation are capable of meaningful self expression of their interests. Therefore, the courts below are correct to limit the authority of parents in institutionalization proceedings. While the intentions of parents may be benevolent, their interests are subordinate to the liberty interests of the person being committed. Studies show that family members are influenced by factors other than the needs of the adult with mental retardation when making the decision whether to institutionalize, and that parental bias in favor of institutionalization changes drastically when parents are made aware of non-institutional placements. Moreover, Petitioner's argument is premised on the stereotype that people with mental retardation are "perpetual children" and lack the ability for meaningful self-expression. A review of the available literature demonstrates that this premise is false.

2) *Amici* and their members are all potential subjects of involuntary institutionalization procedures, and agree with the court below that those procedures involve a significant loss of liberty. The history of such institutionalization is fraught with stereotyping, pseudo-science, and segregation, while currently a concensus exists that people with mental retardation should live in the community. The loss of liberty involves not only segregation from society, but also other deprivations of liberty, including the use of powerful psychiatric tranquilizers as chemical restraints. *Amici* and their members deplore this treatment of themselves and their peers.

ARGUMENT

This case presents important constitutional issues of equal protection and due process in the involuntary institutionalization of persons with mental retardation. These issues of law are well articulated in the briefs of Petitioner, of Respondent, and of the various other *amici curiae* in this matter. Less apparent in those briefs, however, are the personal concerns and abilities of the persons labeled as having mental retardation who face a loss of liberty through involuntary confinement in a state institution. It is imperative that this Court, in its consideration of this matter, take those concerns and abilities into proper account.

For reasons ranging from fear and aversion to paternalistic benevolence, our society has long treated persons labeled as having mental retardation as less-than-equal members of society.[1] One manifestation of this treatment

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[1] In passing the Americans with Disabilities Act, Congress made the following findings, codified at Title 42 U.S.C. section 12101(a):

* * * *

(3) discrimination against individuals with disabilities persists in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services;

* * * *

(5) individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, the discriminatory effects of architectural, transportation,

has been a systematic physical segregation of persons with mental retardation into state institutional settings. Another has been to ignore the voices of persons with mental retardation who seek to speak for themselves in defense of their personal liberty, and to listen instead to the voices of family members who claim that persons with mental retardation are "better off" in environments that abridge their liberty.

This brief will seek to demonstrate that these practices should not be sanctioned by this Court, and that the courts below were correct in restricting state laws that perpetuated them.

I. IN VIEW OF THE CAPABILITY OF PEOPLE WITH MENTAL RETARDATION FOR MEANINGFUL SELF-EXPRESSION, THE COURTS BELOW PLACED PROPER LIMITS UPON THE AUTHORITY OF PARENTS IN INSTITUTIONALIZATION PROCEEDINGS.

While no one disputes the benevolent intentions[2] of most parents, family members, and guardians in institu-

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and communications barriers, overprotective rules and policies, failure to make modifications to existing facilities and practices, exclusionary qualification standards and criteria, segregation, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities(.)

[2] The relationship between parents and their adult children labeled as having mental retardation is complex. No matter how benevolent the parents' intentions, an overly protective, relationship can result in a suppression of self expression on the part of the person labeled as having mental retardation. One person labeled as having mental retardation has described this as follows:

> My mother protected me—it wasn't wrong that she protected me, but there comes a time when someone has to come in and break them away. I can remember trying to be like the other kids and having my mother right there pulling me away—she was always worried about me. You can't force yourself to say to your mother, 'Stop, I can do it myself.' Sometimes I think the pain of being handicapped is that people give you so much

tionalization proceedings, primary consideration must be given to the interests of the person facing commitment as expressed by that person. Thus, the courts below were correct in finding that parents and guardians are "third parties" to the proceedings whose "interests may be adverse to the person facing commitment." *Doe v. Cowherd*, 965 F.2d 109, 113 (6th Cir. 1992). The interests of any person supporting the involuntary institutionalization of a person alleged to have mental retardation (with the loss of liberty inherent in such an outcome) and seeking to appeal a finding of the court that such confinement is inappropriate, are subordinate to the liberty interests of the person resisting the imposition of confinement.

Studies show that family members typically support (and generally initiate) the institutionalization process of their family member with mental retardation. While that position may be reached reluctantly, it is nonetheless influenced frequently by factors which have little to do with the actual needs or abilities of the person with mental retardation. For example, environmental factors such as stress within the family often trigger the request for institutional placement. Serious health problems of a caregiver family member often play a major role, as does the caretaker's advancing age. Black et al., *Individual and Family Factors Associated with Risk of Institutionalization of Mentally Retarded Adults*, 90 Am. J. of Mental Deficiency 271 (1985). The absence of available community-based residential options, such as super-

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> love that it becomes a weight on you and a weight on them. There is no way that you can break from it without hurting them—without bad feelings—guilt. It is like a trap because of the fact that you are restricted to your inner thoughts. After a while you resign yourself to it. The trap is that you can't tell them, 'Let me go.' You have to live with it and suffer. It has to do with pity. Looking back on it I can't say it was wrong. She loved me. You do need special attention, but the right amount.

R. Bogdan and S. Taylor, Inside Out: The Social Meaning of Mental Retardation 37 (1982).

vised or semi-independent living arrangements, often forces a family to seek placement of a person with mental retardation into a state institution. *Id.* at 275. Another study noted that "[s]tressors within the family, the burden of care, and disruption of family relations contributed significantly to the placement request process" for persons over twenty-one years of age. Tausig, *Factors in Family Decision-Making About Placement for Developmentally Disabled Individuals*, 89 Am. J. of Mental Deficiency 352, 358 (1985). Family size is also a factor, as larger families tend to initiate placement more readily than smaller families. Sherman, *Predictors of the Decision to Place Developmentally Disabled Family Members in Residental Care*, 92 Am. J. on Mental Retardation 344, 347 (1988). The same study showed that families with separated or divorced parents were more likely to seek institutionalization of a family member with mental retardation. *Id.* at 347-348.

Therefore, the courts in this matter were correct in finding that the interests of family members are not to be accepted routinely as equivalent to the interests of the person alleged to have mental retardation. This conclusion is even more justified when viewed in light of the degree to which family members' bias toward institutionalization changes when deinstitutionalization eventually occurs.

One study summarized its findings in this regard as follows:

> The majority of families of institutionalized persons are very satisfied with the institutional mode of care.
>
> The majority of families of institutionalized persons oppose deinstitutionalization.
>
> Consideration of deinstitutionalization is very likely to present a crisis for families, and this crisis is as intense as was the initial institutionalization.

Conroy, *Reactions to Deinstitutionalization among Parents of Mentally Retarded Persons*, in Living and Learning in the Least Restrictive Environment 141, 149 (1985).

Another study confirmed these conclusions, noting:

> Our data clearly reveal that the families of institutionalized persons with mental retardation are very much satisfied with current institutional placements. . . It is also possible that the reported level of satisfaction is at least partially attributable to the threat of unknown factors involved in community placement and the hypothesized need to justify a decision to institutionalize their relative many years ago. Parents, in general, do not have enough first-hand knowledge of community programs to enable them to endorse such placement for their son or daughter. Those who have expanded their knowledge base by visiting group homes tend to hold more favorable attitudes toward community placement.

Spreat et al., *Attitudes Toward Deinstitutionalization: National Survey of Families of Institutionalized Persons With Mental Retardation*, 30 Mental Retardation 267, 273 (1987).

The degree of initial family opposition to community relocation of their institutionalized family members with mental retardation, and the extent to which their minds are changed after viewing the results of deinstitutionalization, are systematically recorded in the most detailed and extensive study to date, involving the community relocation of residents of the Pennhurst facility in Pennsylvania. The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis (1985). That study showed that prior to community placement of the Pennhurst residents, only 19% of the residents' family members strongly supported the community residential option; 55% of those family members strongly opposed the community placement. *Id.* at 180. After seeing the results of the community relocation, however, only 4% remained strongly opposed while a full 66% voiced strong support for the new placement. *Id.*

A similar change in attitude is reflected in regard to family members' satisfaction with care provided in state institutions. A 1989 survey reported that parents showed a mean level of satisfaction with the institutional setting of 90.1% while the person with mental retardation was still residing at the institution. After the person with mental retardation moved to a community residential placement, however, the parental approval of the former institutional care dropped in retrospect to 52.3%. The study noted:

> One possible explanation for this difference is that parents who have had the opportunity to see their family member in a small community living arrangement have a different frame of reference and a new perspective about the adequacy of the institution. Once having seen the nature of the community residences, the institution may not look as good as it once did.

Parent Attitudes About Their Daughter's or Son's Residential Placement Before and After Deinstitutionalization, Policy Research Brief, Nov. 1989, at 4.

In sum, this Court should view with some skepticism assertions by a state and by parent or family groups that parents and family members "know what is best" for adults with mental retardation and should be considered parties to the institutionalization process. In fact, there are many situations where family members are not able to determine what is best for their child, at least from the point of view of the child.

The courts below correctly reasoned that the parental relationship to a minor child which was decisive in *Parham v. J.R.*, 442 U.S. 584 (1979), was not controlling in a case involving adult offspring.[3] The Kentucky proce-

[3] " 'Once someone becomes an adult, one's parents lose that degree of authority found so crucial in *Parham*.' " *Doe v. Austin*, 848 F.2d 1386 (6th Cir. 1988), quoting *Clark v. Cohen*, 613 F. Supp. 684, 699 (E.D. Pa. 1985).

dures at issue, unlike those in *Parham*, apply to adults alleged to have mental retardation subject to institutionalization, as well as to minor children.

Moreover, unlike *Parham*, the authority granted to third persons by the Kentucky statutes extends far beyond parents, encompassing all "immediate family members" as well as parents and legal guardians.[4] Such extension of family members' authority into the adulthood of the affected relative constitutes neither good law nor good policy—an adult facing confinement in an institution must overcome quite enough hurdles to defend his/her liberty interest without being forced to overcome the opposition of a family member operating "as if a party to the proceedings." KRS 202B.160(3).[5]

Petitioner's reliance upon the authority of *Parham* implicitly equates people with mental retardation and minor

[4] *E.g.*, KRS 202B.160:

> (3) Guardians and immediate family members of the respondent shall be allowed to attend all hearings, conferences or similar proceedings; may be represented by private counsel, if desired; may participate in the hearings or conferences as if a party to the proceedings; may cross-examine witnesses if desired; and shall have standing to appeal any adverse decision. (Enact. Acts 1990, ch. 147, Sec. 15, effective July 13, 1990.)

[5] In their attempt to urge a paternalistic approach to this matter, Concerned Families of Hazelwood Center et al. repeatedly (and erroneously) characterize this case as involving "severely and profoundly retarded" persons. *Amicus Curiae* Brief of the Concerned Families of Hazelwood Center et al., at 1, 3, 5, 6, 7, 8, 9, 10, 11, 13, 18. In fact, the Kentucky statutes at issue apply equally to persons with mild, moderate, severe, and profound mental retardation. The District Court below found in its Memorandum Opinion of January 9, 1986, in this matter that of the eight residents of Kentucky's institutions for persons with mental retardation at that time, one hundred residents were persons with mild or moderate mental retardation. Joint Appendix of Petitioner and Respondents, at 64. Since that time, the actual numbers may have changed but the statutory language remains all-encompassing.

children.[6] This inherently assumes that people with mental retardation lack both decision-making capacity and expressive ability.

Those who are labeled as having mental retardation constantly face the stereotype, pervasive throughout our entire society, that people with mental retardation are "perpetual children," incapable of structuring their own lives or even of knowing what they want in their lives. That stereotype, more than any other, works to deprive people with mental retardation of the fundamental right of personal autonomy taken for granted by other adult citizens of this nation.

In fact, we, the members of the *amici* organizations here, do know what we want in our lives; we ask only that our voices be heard as the voices of other adults are heard when life choices are made. Not all of us can communicate our thoughts in sophisticated ways, but each of us can communicate.

Amici members all have an interest in what has come to be known as "quality of life". One person labeled as having mental retardation, Connie Martinez, has stated it this way:

> So the first thing for the professionals and the parents to understand is that we can have a good quality of life if we have control over our own lives and if we have the help we need to keep that control and independence in our own lives. We don't need KEEPERS, we need TEACHERS.

Martinez, *A Dream for Myself*, in Quality of Life: Perspectives and Issues 1, 4 (1990) (emphasis in original).

Many professionals have gradually accepted that philosophy. One such professional has written:

> Quality of life is a matter of consumer (i.e., "consumer" of mental retardation services) rather than

[6] Brief of Petitioner at 22.

> professional definition. Quality of life issues should be defined by consumers and other citizens rather than by professionals in the field. Ultimately it is how the individual perceives and evaluates his own situation, rather than how others see him, that determines the quality of life he or she experiences.

Schalock, *Preface* to Quality of Life: Perspectives and Issues, *supra* p. 12, at x.

It is apparent that persons with mental retardation have something to say about the topic of confinement in institutions, and are becoming more vocal in expressing their thoughts and feelings. Sometimes they speak on a collective level, as with the following resolution from a national organization of persons with disabilities, Self-Advocates Becoming Empowered:

> The National Self-Advocacy Steering Committee understands that People First of Tennessee has filed a lawsuit against the State of Tennessee to close the institution at Arlington, TN. We agree that their case is a strong one. A number of us have been in institutions where we were hurt physically and emotionally. Our members have had experiences where we were tied up in restraints, pulled by our hair, lemon juice squirted in our faces, electric shock used on our bodies to control us so that we would be knocked out on medication. Emotionally we had no privacy in showers and in the restrooms, we were left in our bed all day with nothing to do. We were denied relationships with men and women. We were never allowed to make choices and decisions for ourselves and never knew that we could. We stand behind People First of Tennessee 100 percent. We need to see more money out of the institutions and supporting people to live in their own place and having the opportunity to work. The State of Tennessee should spend the money for people with disabilities in the community and not for institution places.

Legislative Committee Report, adopted by National Self-Advocacy Steering Committee, Self-Advocates Becoming Empowered (December 4, 1992).

At other times they speak as individuals. Roberto Reyes, a person labeled as having mild mental retardation who spent eight years in an institution for persons with mental retardation, described his experience:

> Being there years in a place like that, it gets anybody down. It's not like being in jail. In jail, you go to jail and you know when you're gonna get out, but being in an institution you don't know when you're going to get out. I wanted to get out . . . and the only way I could get out of there was by getting sterilized.

Ward, *"I've Seen It All! . . . Well, Just About All,"* in "I've Seen It All!" Lives of Older Persons with Mental Retardation in the Community 71, 75-76 (1991).

Some persons with mental retardation must use nonverbal methods of communication to tell people what they think, but can still express themselves, if others have the patience to listen. Even those with the label of profound mental retardation can communicate how they feel about being sent to institutions. Nicholas Romeo, a person labeled as having profound mental retardation and plaintiff in the landmark case of *Youngberg v. Romeo*, 457 U.S. 307 (1982), who resided at the Pennhurst facility in Pennsylvania, was described by the institution's psychologists upon his admission to the facility in their report as follows:

> He was toilet-trained, they noted, had learned his way to the bathroom and dining room, and had started approaching the Pennhurst aides, taking their hands and guiding them out of the ward.
>
> "The only way of expressing his needs and desires is one of taking another's hand and pulling him out. This seems to mean 'going away' rather than going out."

Woestendiek, "The Unwitting Revolutionary of Pennhurst", The Philadelphia Inquirer Magazine, May 27, 1984, at 18, 21.

Aversion to institutional confinement is a consistently recurring theme in the self-expression of persons with mental retardation. The most frequent description of institutional life is a comparison to jail. In describing how former residents of an institution for persons with mental retardation pursue recreational activities in the community, one study noted:

> Another central concern for the former patients is the use of leisure time. The ex-patients pursue "recreation," or just plain "fun," with a single-mindedness that is impressive. The former patients themselves trace their relentless pursuit of happiness to their long history of being deprived of the right to seek leisure-time pleasures when and how they wished. They speak of lives—before hospitalization—of restricted recreation, and they shudder at the memory of their hospital years, during which they always felt controlled, scheduled, and restricted: "We was always cooped in and pushed around. We couldn't do what we wanted in that place. It was like a jail with all them rules and locks on the doors." The freedom of life in the community intensifies the search for "fun," for the full and free use of leisure time. To fill spare time with "fun" is a central focus for the discharged ex-patient. As one man phrased it: "I feel like I got a right to fun now that I'm out, to make up for all the years I was in that place."

R. Edgerton, The Cloak of Competence—Stigma in the Lives of the Mentally Retarded 126 (1967).

Thus, the premise underlying Petitioner's argument, that persons with mental retardation lack capacity or the expressive ability to make decisions regarding institutionalization, cannot withstand a review of the available literature, which demonstrates the abilities and concerns of persons with mental retardation in this area. The

sounder proposition is to protect as paramount the interest of the person with mental retardation in exercising judgment over and control of these decisions.

II. INSTITUTIONALIZATION INTRUDES UPON VALUED LIBERTY INTERESTS.

As persons with mental retardation, we, the members of the organizations filing this brief, are potential subjects of involuntary institutionalization procedures. *Amici* believe that the court below was entirely correct in ruling that "[t]he mentally ill and mentally retarded are identical insofar as they lose their personal liberty by involuntary institutionalization." *Doe v. Cowherd*, 965 F.2d 109, 113 (6th Cir. 1992). Courts and professional researchers alike have confirmed the importance of this loss of liberty.

It is beyond dispute that involuntary commitment to an institutional setting entails a significant deprivation of liberty.[7] It is by no means inappropriate that a state entity seeking to deprive a person of a liberty interest be held to a high standard of proof to effect that deprivation. Petitioner would have this Court believe that the safeguard against unwarranted confinement offered by the "beyond a reasonable doubt" standard of proof actually "penalizes"[8] and "burdens"[9] the person whose

[7] *Addington v. Texas*, 441 U.S. 418, 425 (1979) ("civil commitment for any purpose constitutes a significant deprivation of liberty"); see also *Humphrey v. Cady*, 405 U.S. 504, 509 (1972), describing psychiatric commitment as a "massive curtailment of liberty"; see also *Vitek v. Jones*, 445 U.S. 480, 493 (1980) (even a person convicted of a crime has a protected liberty interest in regard to involuntary institutional care).

[8] "The Equal Protection Clause does not require that the mentally retarded be penalized by an inappropriate standard of evidence in their involuntary commitment proceedings simply because a State has improvidently required the inappropriate criminal law standard for its mentally ill." Brief for Petitioner at 19-20.

[9] "The difference in the standards of evidence imposes no burden upon the mentally retarded. Rather, it simply frees them from a

liberty interest is in jeopardy. Petitioner's implicit assumption is that liberty is unimportant to persons with mental retardation. *Amici* wish to emphasize to the Court that that assumption is fundamentally and frighteningly wrong.

The history of the institutionalization of persons with mental retardation is also a history of society's attitudes towards persons with mental retardation. In colonial times persons with a variety of disabilities were cared for by their families. In that more agrarian, less technical age prior to urbanization and industrialization, persons with disabilities were more easily assimilated into the daily life of the general population. The nation's first institution specifically for persons with mental retardation opened in Massachusetts in 1848. Early institutions were few (there were only ten in the nation by 1880), and were largely devoted to humanitarian care and training.

The latter part of the nineteenth century witnessed a profound change in how society, and the professionals of the time, viewed people with disabilities, especially those who were then called "feebleminded."[10]

> In attempting to understand and explain the social problems of their times, social theorists . . . began to apply evolutionary theory to the development of society. The cause of the spread of poverty, crime, immorality, and other social evils throughout society, they reasoned, was the proliferation of people with defective genes. The feebleminded gradually came to be singled out as especially dangerous carriers of social disease. These theories were translated into a program of social action known as the eugenics movement.

burden which was imposed unnecessarily, and perhaps unwisely, upon the mentally ill." Brief for Petitioner at 30.

[10] Persons with mental retardation have been labeled "idiots", "morons", "imbeciles", "feebleminded", "mentally deficient", "mentally defective", and "mentally retarded."

Taylor and Searl, *The Disabled in America: History, Policy, and Trends*, in Understanding Exceptional Children and Youth 5, 13 (P. Knoblock ed. 1987).

In a manifesto of this eugenics movement one "charitable" organization of the time, the American Breeders Association, wrote in 1913 that the so-called "feebleminded" "must generally be considered as socially unfit and their supply should if possible be eliminated from the human stock if we would maintain and raise the quality essential to the progress of our nation and our race." *Id.* at 15.

The attitudes and beliefs of the leaders of the eugenics movement led to restrictive policies towards persons with mental retardation including segregation, sterilization,[11] restrictive immigration and, among some leaders, consid-

[11] By 1926 twenty-three states had laws requiring sterilization of persons labeled as having mental retardation or making sterilization a prerequisite to their release from institutional confinement. *Id.* at 16. At one point even this Court approved such practice. *Buck v. Bell*, 274 U.S. 200 (1927). Indeed, even in 1942, in the case which struck down sterilization of criminals, *Skinner v. Oklahoma*, 316 U.S. 535 (1942), members of this Court continued to speak with approval, not repudiation, of the principle of eugenics as applied to persons with mental retardation:

> I also think the present plan to sterilize the individual in pursuit of a eugenic plan to eliminate from the race characteristics that are only vaguely identified and which in our present state of knowledge are uncertain as to transmissibility presents other constitutional questions of gravity. This Court has sustained such an experiment with respect to an imbecile, a person with definite and observable characteristics where the condition had persisted through three generations and afforded grounds for the belief that it was transmissible and would continue to manifest itself in generations to come. *Buck v. Bell.*

Skinner v. Oklahoma, supra, at 546 (Jackson, J., concurring).

> Undoubtedly a state may, after appropriate inquiry, constitutionally interfere with the personal liberty of the individual to prevent the transmission by inheritance of his socially injurious tendencies. *Buck v. Bell.*

Skinner v. Oklahoma, supra, at 544 (Stone, C.J., concurring).

eration of euthanasia. These attitudes "so pervaded public and professional thinking that many of the views expressed during the period persist today." *Id.* at 16.

Throughout this period and beyond, the size and number of institutions for persons with mental retardation expanded rapidly. Although by 1930 the eugenics movement had been scientifically discredited and its leaders had largely recanted their views, institutions continued to expand. Between 1930 and 1970 the number of public institutions for persons with mental retardation increased from 77 to 190, while their populations grew from 68,035 to a 1967 peak of 194,650. *Id.* at 20.

The late 1960s and the 1970s saw not only the beginning of deinstitutionalization (the movement of residents of state institutions for mental retardation into communiy-based residential options) but also a series of exposés of the treatment of persons with disabilities in institutions. Litigation in many states successfully challenged the conditions of these institutions as unconstitutional. Persons with mental retardation experienced deplorable conditions, which are well documented in the litigation nationwide.

It is interesting to note that although the nation's overall institutional population continues to decline, Kentucky is one of the very few states with an actual increase in its institutional census in recent years. Nationally the institutional census has declined from 149,169 in 1977 to 109,619 in 1984 to 91,440 in 1988. That is an overall decrease of 16.6% nationally between 1984 and 1988. Only four states (one of which was Kentucky) showed increases in institutional census figures in the period of 1984-1988. D. Braddock et al., The State of the States in Developmental Disabilities 13 (1990).

Overall, the movement of people with mental retardation from institutional confinement to community resi-

dences is now firmly established. As one professional analysis has noted:

> The issue of "institutions versus the community" which has dominated the field of developmental disabilities for nearly 20 years is yesterday's issue. That people with severe disabilities can be served in the community is no longer an unproven proposition. An increasing number of places across the country have found ways to support people with the most challenging needs in the community.

Taylor and Racino, *Community Living*, in Critical Issues in the Lives of People With Severe Disabilities 235 (1991).

The impact of involuntary institutionalization upon the institutionalized person's liberty interests is real, is tangible, and is felt by that person in a number of varied ways. For example, Alan Lessard of Tacoma, Washington, who was forced to live at an institutional setting, Rainer School, for forty-eight years until he moved to a community residence in 1990, stated his feelings as follows:

> No one should have to live in an institution. It's not home. Their home is right out here with everyone else.
>
> I went to Rainer School when I was a small boy because my mom and dad couldn't take care of me. I did carpentry there. I missed a lot.
>
> Now, I can take the bus by myself and I like that. Nobody comes with me.
>
> When I was at the institution, no one would let me do anything by myself. I don't feel so good that my friends are still there. I visit them and they visit me. They don't belong there.

V. Medgyesi, No More B.S.! A Realistic Survival Guide for Disability Rights Activists 29 (People First of Washington 1992) (copy provided to Librarian of Supreme Court Library).

Nonetheless, the basic purpose of Petitioner's lowering of its standard of proof for institutionalization of persons with mental retardation is to facilitate the involuntary confinement of persons with mental retardation in its state institutions. To justify such a facilitated process, Petitioner emphasizes alleged positive benefits of institutionalization, which would presumably include habilitation [12] and adequate health care. In fact, however, studies indicate that persons residing in state institutions for persons with mental retardation typically receive neither superior habilitation nor superior health care when compared to residents of less confining community residential facilities.

In regard to habilitative progress, researchers at the University of Minnesota summarized in 1989 the results of their investigation of existing research literature as follows:

> All eight experimental/contrast group studies reported statistically significant greater achievement in either overall adaptive behavior or in the basic self-care/domestic skill domain for those who moved to community living arrangements relative to those who remained in state institutions. . . .
>
> Among the longitudinal studies, 5 of the 10 reported statistically significant increases in overall adaptive behavior or in the basic self-care/domestic skill area after movement to the community. . . .
>
> Overall, 13 of the 18 studies summarized for this report noted statistically significant improvements in either overall adaptive behavior or in the basic self-care/domestic skill area. Seventeen of 18 studies showed at least a tendency toward improved adaptive

[12] The liberty interests of an involuntarily institutionalized person with mental retardation require that the state provide habilitation consisting of, at least, minimally adequate or reasonable training to ensure safety and freedom from undue restraint. *Youngberg v. Romeo*, 457 U.S. 307 (1982).

> behavior associated with movement to the community. . . . Therefore, one must conclude that available research provides considerable support for the assertion that people who move from state institutions to small community living arrangements can be expected to experience increases in adaptive behavior skills.

Deinstitutionalization of Persons with Mental Retardation: The Impact on Daily Living Skills, Policy Research Brief, March 1989, at 2.

Similar studies question the presumption that institutionalized persons with mental retardation are "better off" in regard to health care:

> The available research does not clearly support one type of residential setting as superior to the others from a health and health care perspective. . . .
>
> The majority of studies noted positive health related outcome of individuals who were deinstitutionalized. In fact, one study found that many previously unrecognized medical conditions that were present while individuals lived in institutions were identified when they moved into the community.

Living in the Community: Persons with Mental Retardation and Allied Medical Conditions, Policy Research Brief, June 1990, at 2.

Moreover, despite Petitioner's protestation to the contrary,[13] use of psychotropic drugs[14] is widespread at institutions for persons with mental retardation, far more widespread, in fact, than at alternative residential settings. A 1989 survey of an entire institutional population of a large state revealed that 35.4% of residents at state institutions for persons with mental retardation were

[13] "Mental retardation . . . rarely involves treatment through psychotropic medications." Brief for Petitioner at 32.

[14] Institutionalized persons possess a substantial liberty interest in avoiding the unwarranted imposition of psychotropic drugs. *Washington v. Harper*, 494 U.S. 210 (1990).

given psychotropic drugs. Stone et al., *Prevalence and Prediction of Psychotropic Drug Use in California Developmental Centers*, 93 Am. J. on Mental Retardation 627 (1989). More revealing, and more alarming, are the figures from a 1988 study which show that fully 39.9% of persons with mental retardation living in institutions were administered psychotropic drugs, while only 24.8% of persons in community care facilities and 10.1% of persons living with relatives received such drugs. Jacobson, *Problem Behavior and Psychiatric Impairment Within a Developmentally Disabled Population III: Psychotropic Medication*, 9 Research in Developmental Disabilities 23, 30 (1988).

The debilitating effects of such drugs are described in the following typical account of a person (Pattie Burt) who formerly resided in an institution for persons labeled as having mental retardation:

> When I was on Thorazine I was getting them and throwing them down the toilet. . . . I didn't want to take them. I didn't like them. They just made me sleepy and tired. I couldn't study in school. I couldn't go to school and work or anything like that. I would just fall asleep. They told the doctor about me throwing them away so she put me on liquid medication and I had to stand in front of the attendant until it was all down. Then that stuff began to burn my tongue so they put me back on the pills.
>
> There were a lot of people on tranquilizers—maybe 50 percent of the patients. You could tell who was on it because they would be falling asleep. A lot of them were quiet. They couldn't do some of the things they were doing before.

R. Bogdan and S. Taylor, Inside Out: The Social Meaning of Mental Retardation 122 (1982).

The history of institutionalization of people with mental retardation is a history of failure to recognize their legitimate liberty interests. It is also a personal nightmare for

many of those people, including some *amici* members. This Court should recognize that the courts below properly limited the state laws at issue.

CONCLUSION

In the early 1980s a group of persons with mental retardation from Austria presented the following statement at the United Nations:

> We are people first and only secondly handicapped.
> We wish to speak for our rights and let other people know we exist.
> We want to explain to our fellow human beings that we can live and work in a community.
> We want to show that we have rights and responsibilities like other people.
> Our voice is new.
> We must first learn to speak.
> We ask everyone to learn to understand our voices.
> We need people who teach us to speak. People who believe in us.
> Mentally retarded persons do not want to live in terrible institutions.
> We want to live in the community.

Reprinted in Taylor and Searl, *supra* p. 18, at 25-26.

As is demonstrated ably by this statement and by the materials presented in this brief, people who are labeled as having mental retardation do not deserve to be treated differently, nor is there any basis for treating them differently, than other people when faced with the enormous invasion of liberty that occurs when involuntarily committed to an institution. The stigma, the invasive treatment, the lack of privacy documented here are ample reason for *amici* and our members to oppose a broadening of a state's powers in this arena.

Similarly, there is no need to give parents of adults with mental retardation a greater or even paramount interest in the commitment process. In spite of the good

intentions of the parents, there remains a significant need for external scrutiny of commitment decisions. Furthermore, this scrutiny must occur in a forum where the person alleged to have mental retardation has the opportunity to speak for himself or herself, just as *amici* have spoken to this Court through this brief.

For these reasons, *amici curiae* urge that this Court uphold the ruling of the U.S. Sixth Circuit Court of Appeals in this case.

Respectfully submitted,

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